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History's changing view

**Alastair Campbell** talking straight

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EDITORIAL ENGAGEMENT FOR BRANDS



## editorial

# Death by bad judgement

Outrage is not a fashionable emotion these days. The current trend is for us all to express ourselves in moderate tones and reason rather than raw reaction.

But how are we to be expected not to rail against circumstances which result in an 80-year-old woman writing to *Disability Now* literally in fear of her life?

On a recent hospital visit she was left to wait between appointments with medical practitioners and was given her notes to hold. On looking through them she was alarmed to discover that someone had written on them the instruction – and it is just that, an instruction – "Do not resuscitate".

Just to be clear, one medical practitioner has specifically and without qualification told other medical practitioners that, in any circumstances where this person finds themselves close to death, no attempt is to be made to prolong or, even more worryingly, save their life.

I'm sorry, but I think that outrage is well in order here. What kind of civilised society is it that gives one group of people – doctors – 66 What kind of civilised society is it that gives one group of people - doctors - the right to a call over life or death for another group - disabled people 99

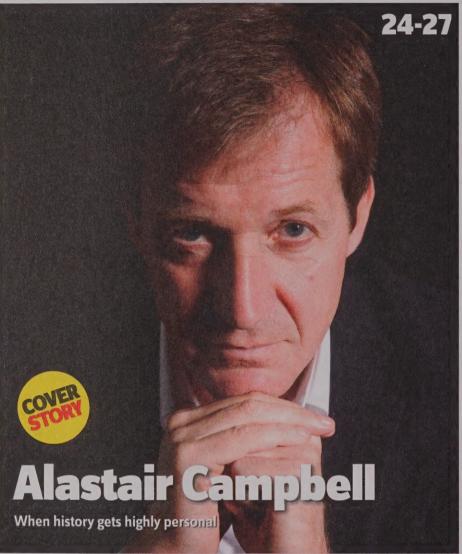
the right to a call over life or death for another group – disabled people. Us.

Yet more cause for astonishment and outrage derives from the fact that there will be people reading this to whom this is not only a familiar tale, but a fact of their own lives.

More astonishing and outrageous still is the fact that such judgements as to the value of the lives of individual patients are still being made, despite the fact that we are told by representatives of the medical profession that this is no longer permissible and should not be/is not happening.

Surely there are no circumstances when, without their expressly given permission, anyone's life should be terminated on the judgement, assumption or whim of another.

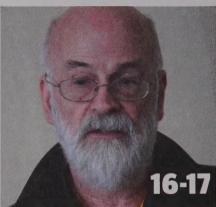
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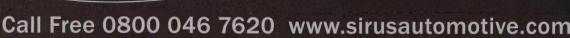


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## newsview

## **Cuts fears remain after judgement**

Advocates and activists continue to be fearful of an ongoing cutting agenda by Birmingham City Council despite judicial reassurance as **Sunil Peck** reports

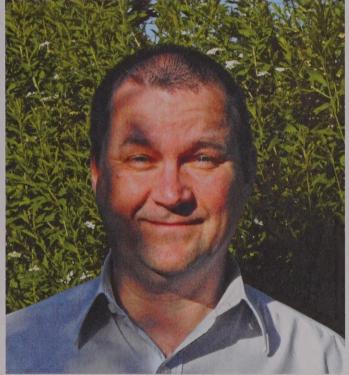
People in Birmingham fear losing local authorityfunded support despite a High Court ruling overturning the Council's decision to restrict eligibility to people assessed as having critical needs.

Birmingham City Council's programme of cuts included savings of £51 million from its adult social care spending in 2011/12 and a major part of this was to be achieved by withdrawing Council-funded services from people assessed as having substantial needs.

The Council had said that it would signpost them to possible alternative sources of support, such as the voluntary sector, but no detailed plans were in place when the Council made its decision.

But a judge upheld a judicial review sought by four disabled adults assessed as having substantial needs and who had claimed that the Council failed to give proper consideration to the impact of restricting councilfunded services to people with critical needs.

But as the High Court ruling relates to the process the Council went through



rather than the decision itself, disabled people in Birmingham are concerned that the cuts will be made in the future.

Sandra Daniels, Coordinator of People First Birmingham, said that its members were concerned because organisations in the voluntary sector which may have been in a position to provide support were struggling to survive.

She said: "People are worried about their nighttime support being taken away so they'll be left alone to cook, lock doors and turn everything off before they go to bed."

Pete Millington (pictured), Information and Community Empowerment Manager at Birmingham Disability Resource Centre, said that the majority of people he supports fall into the substantial needs bracket.

He said: "I know someone who is independent but who is worried. He has substantial communication and mobility difficulties yet he works. But if his support

is withdrawn, something which looks like a strong possibility, he will be unable to work."

He added that any future cuts which hit people who need support to look after themselves or attend day centres and colleges risked creating a situation where they would end up falling into the critical need bracket as a consequence.

Karen Ashton, the solicitor who represented three of the disabled people who sought the judicial review, said that even if the cuts were made in the future, the ruling was significant because it meant that local authorities would have to consider the needs of disabled people when deciding where to make cuts.

She said: "In cashstrapped times such as these, the public sector must do more to avoid the consequences of cuts falling on those who are least able to bear them. This is not just a moral obligation, but a legal one."

Birmingham City Council was yet to decide whether or not to appeal as Disability Now went to press.



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## newsupdate



## **Voices of the hardest hit**

Ian Macrae

Disabled people from among the thousands who took part in The Hardest Hit demonstration have been telling Disability Now why they marched.

Jaspal Dhani, Chief Executive of the United Kingdom Disabled People's Council (UKDPC) said that cuts being made under government welfare reform proposals would have far reaching effects.

"I know that if Disability Living Allowance (DLA) was cut tomorrow, I'd not be able to afford to travel. Losing DLA would mean I'd lose my car. Losing my car

would mean I'd lose my iob and that would mean that my family would be put at risk.

"The situation is becoming so dire that disabled people's lives are being put at risk."

He went on to speak of the possibility of further actions in future.

"If this doesn't have some kind of impact then we'll return to the streets with bigger and better marches. We'll encourage people to take action locally too."

Estimates put the number of marchers at around five thousand.

One of the speakers at a rally before the march was

Chair of Inclusion London Kirsten Hearn. Reflecting afterwards on the significance of the march, she told Disability Now: "It is the largest gathering of deaf and disabled people together in many years. We are angry and we showed it!"

Of her own motivation for marching she said: "I wanted to be with my deaf and disabled sisters and brothers engaged together in an act of solidarity that shows disabled people as strong and resisting rather than passively submissive. I wanted to counter that negative stereotype of the beleaguered benighted

afflicted crips!"

Asked whether the march would have any impact on the Government she said: "What will make a difference is the conversations that deaf and disabled people had with their MPs. At least when MPs vote on cuts they will have met and connected in some way with someone who is going to be directly affected. Anything that brakes the stranglehold of the stereotype of disabled benefit scrounger can only help."

Disabled Labour MP and Chair of the Commons Select Committee on Work and Pensions, Dame Anne Begg also spoke at the rally and attended the march. She too said that she believed that the mass lobby of MPs by disabled people would be likely to have lasting value.

"I suspect that the most effective part of the day was the lobbying of individual MPs by the people who attended. MPs do listen to their constituents and so that face-to-face meeting is very important and will go much further in persuading government MPs that what the Government is proposing is wrong. It is much harder for an MP to dismiss the views of a constituent when they are telling them about their real life experience.

## newsupdate

## Protest targets assessment contractor

**Annie Makoff** 

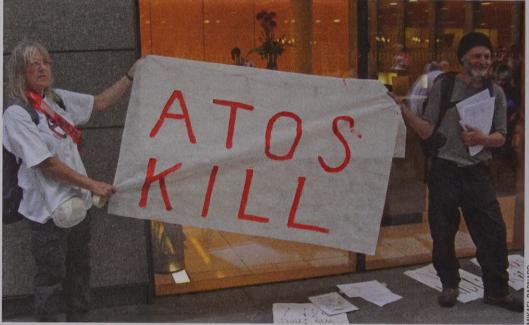
The London headquarters of ATOS, the corporation that carries out controversial benefit assessments, was the latest target for action by disability campaigning group Disabled People Against Cuts (DPAC).

The group claims that benefit claimants are subjected to unfair and discriminatory assessments carried out under contract by the company which have resulted in record numbers of rejected claims for Employment Support Allowance (ESA).

ATOS has just signed a £300million deal with the Department of Work and Pensions to reassess ESA claimants until 2015.

Kicking off a week of action against government welfare reform and ATOS, the protest was attended by members of DPAC, the Euston branch of the Public and Commercial Services Union, and several groups of disability activists.

DPAC founder Linda Burnip who organised the protest said: "A lot of people don't know the crucial part ATOS plays in the assessments. Today is about educating people,



getting the news out and making sure that ATOS know that we're not giving up the fight against them."

She added: "I know hundreds of people who have lost everything. If you lose Incapacity Benefit, you lose Disability Living Allowance (DLA). If you lose DLA you lose all the other benefits you are entitled to. It is a massive knock-on effect."

Disability activist and DPAC member, Adam Lotun was also at the protest. Having had his DLA taken away based on the assumption that he was "high-functioning", he lost all his other benefits, his car, and his job. He said:

"Everything at home is the same height as my wheelchair so I use my stick at home. The assessor assumed I had lied about my wheelchair and took everything away from me. Because they took my car away too, I couldn't get to work and lost my job. I'm still waiting for a stairlift and a downstairs toilet. I've got eight-week-old twins and I can barely carry them."

Other people at the protest voiced concern about the vicious circle the Government is creating for disabled people, by denying them benefits which help pay for crucial support networks and services,

therefore forcing many into unemployment and poverty.

"We've already seen an increase in suicide rates among disabled people," Adam Lotun said. "Many are unable to afford medication, transport and their own support workers. These support workers are now becoming unemployed – where will it end?"

He added: "In the eyes of ATOS, Stephen Hawking isn't disabled anymore because he has got a wheelchair and a communication device. So if you have a mobility aid you are no longer disabled, so your claim will be rejected. The medical model of disability reigns."



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## ruthpatrick

## Closure opens gap for students

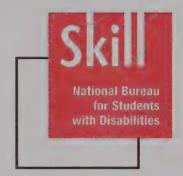


As the class of 2011 traipses out of the playground and slowly into adulthood Ruth Patrick laments the passing of an organisation which gave valuable help and support to disabled students

ontinuing in further and higher education is a great way to learn new skills, become more "employable", whilst also having a fantastic time meeting new friends and lovers and enjoying recently-won freedoms.

The transition from school into higher or further education can be even more challenging for disabled people who have to navigate new, complex forms of funding and form relationships with equality units and support staff. Sadly, from April 2011, one organisation that played a particularly critical role in helping disabled students successfully enter and sustain educational careers post-school will no longer be able to provide such support.

Skill: the National Bureau for Students with Disabilities, the only pandisability charity providing help and advice to disabled students, has gone into liquidation following funding issues. Further



details are unavailable, but it is likely that the combination of a government set on cutting the much-overhyped deficit and a broader "age of austerity measures" have taken their toll.

For more than 40 years, Skill offered much needed help and advice to disabled students via its helpline, information booklets and events. Skill also performed a critical policy role in lobbying government for more progressive and enabling support to ensure that disabled people have equal access to the very best higher and further education. The role played by Skill remains essential given enduring issues with the system of financial support for disabled

students (the Disabled Student's Allowance) as well as ongoing battles in persuading universities and apprenticeship providers to become truly "accessible" for all. Indeed, disabled people remain underrepresented in both higher and further education with latest figures showing that while 41% of non-disabled people have experienced higher education by the age of 19, the comparable figure for disabled people is 28%.

In a creative and confident response to Skill's closure nationally, the Scottish wing of the charity has announced that it is seeking to continue its important work, either by setting up as a new organisation or by joining up with an existing charity. The former employees of Skill are lobbying the Holyrood government and working hard to try and create a future where disabled people continue to receive the specialist help they need to prosper in higher and further

66 It is likely that the combination of a government set on cutting the much-overhyped deficit and a broader 'age of austerity measures' have taken their toll

education. The response of the Skill Scotland team shows grim determination to carry on and push forward, despite the many hurdles placed in their path. The team are united in seeking to create a better future for their fellow citizens by ensuring that Skill Scotland's role is not lost. Could this be the real "big society" in action? It's just a shame that to realise David Cameron's vision it is first necessary to cut, cut, cut - causing untold damage - particularly to those many services which will not be rescued by a second-chance-brigade.

 For more information about the Scottish campaign and to sign the petition for the continuity of Skill: Scotland in some form see: supportdisabled studentsinscotland.yolasite .com

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## disabilityrights

isabled people are "unlikely" to enjoy full equality by the vear 2025. according to the new Chair of the Government's advisory body of disabled people, Equality 2025.

Speaking to *Disability* Now soon after her appointment as Chair of the body originally set up in 2006 to give disabled people a voice in government circles. Dr Rachel Perkins said: "2025 for equal citizenship does seem a tall order doesn't it."

A clinical psychologist and a user of mental health services. Dr Perkins was voted Champion of the Year by the mental health charity Mind in 2010 (pictured). She worked in mental health services for 30 years and is involved in areas including the development of personal health budgets, the external scrutiny group of the review of Work Capability Assessment. mental, intellectual and cognitive descriptors, the **Equality and Human Rights** Commission disabilityrelated harassment advisory group and the Stakeholder Coalition on Disability and Employment.

"Since the 1990s I've looked at and written about the lives of people with mental health conditions within a social model framework. An important



# New chair equivocal on equality mission

As she takes up her new role as Chair of Equality 2025, Dr Rachel Perkins tells Sunil Peck that she's less than hopeful about achieving the ultimate goal

turning point for me was going to America in the 1990s and meeting activists in the mental health user/survivor community like Judi Chamberlin and Andy Imparato who were working as part of a broader disability movement. It struck me as being incredibly powerful and I began to see the parallels between user/survivor

ideals about recovery and mental health and the independent living movement."

Dr Perkins's three year term as Chair of Equality 2025 began on 1 April. She says that even though full equality might not be a reality until years after 2025, the body does have a significant role to play in ensuring disability

equality remains on the political agenda.

"The advice we give is confidential so we are consulted early on in policy development, so there maybe ways that we can nudge and influence. Our previous chair, Rowen Jade, [who died last year] had developed an extremely good reputation for Equality 2025 across government,

and I hope to be able to build on the influence she managed to exert."

In 2010, the Labour Government cut the number of members in the body from a maximum of 25 to eight and turned it from a body which consulted disabled people and fed their views back to ministers into an advisory body.

Like her highly regarded predecessor Rowen Jade, Dr Perkins is passionate about achieving greater equality. But her undoubted drive is unlikely to be enough to convince people outside

Our job is not to provide leadership for the disability movement. We have user-led and disabled people's organisations which are representative of disabled people

Equality 2025, who are unaware of who its members meet and what they say, that the body does wield genuine political clout.

She does stress that the

body is a confidential advisory group and not a campaigning organisation.

"That doesn't mean that members don't have contacts across the disability movement, but our job is not to provide leadership for the disability movement. We have user-led and disabled people's organisations which are representative of disabled people."

Asked whether she thought the Government's spending cuts and welfare reforms represented an attack on disabled people. Dr Perkins said: "I don't

know how much that is a deliberate plot against disabled people, I'm not sure that's the case. But the consequences of some of the measures taken in a recession could have devastating effects on the lives of some disabled people. But that makes it all the more important to make sure that disability issues are kept centre stage."

Equality 2025's work plan for the coming year is yet to be published and Dr Perkins was unable to go into detail about the issues it would be focussing on.

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## mediawatch

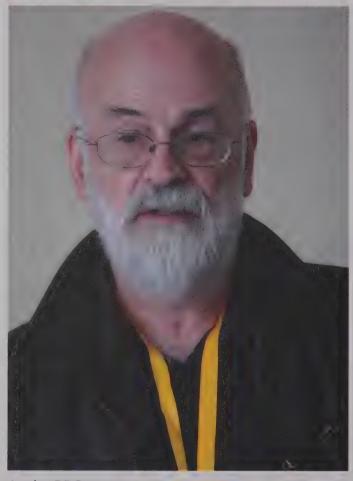
## Death doc sparks Beeb bias row

he BBC has been accused of being a "cheerleader" for assisted suicide by disability campaigners and organisations, after it was announced that the broadcaster would be screening a documentary presented by Sir Terry Pratchett (pictured) featuring a man ending his life at the infamous Dignitas clinic in Switzerland.

In Terry Pratchett:
Choosing To Die, due to be broadcast in June, the author, who has Alzheimer's disease, travels to the Swiss-based clinic with a 71-year-old man with motor neurone disease, and is with him as he dies.

It will not be the first time that an assisted suicide will have been broadcast on British television – in 2008 Sky Real Lives screened Right To Die? in which Craig Ewert, who also had motor neurone disease, was featured travelling to Switzerland to die.

Campaigners against assisted suicide have criticised the BBC's decision to screen the documentary, not just because of its content, but over concerns that the corporation is focussing too heavily on the arguments of the right to die community.



As the BBC prepares to screen a programme in which Sir Terry Pratchett travels to Switzerland with a man who wants to end his life, campaigners have lined up to accuse the BBC of bias reports

Paul Carter

Dr Peter Saunders, Director of Care Not Killing said that the programme would be the sixth in three years on British television that supported or was sympathetic to, the issue of assisted death.

He said: "The BBC is

acting like a cheerleader for legalising assisted suicide.

"It is regrettable that a man's death will be shown on screen but we are also concerned that this documentary will not be balanced.

"Given Sir Terry

Pratchett's position, the fear is that it will show all the supposed benefits of assisted death with very little redress."

Sir Terry himself said that he remained a "firm believer" in assisted suicide.

"I believe everybody possessed of a debilitating and incurable disease should be allowed to pick the hour of their death," he said, adding that he wanted to find out more in case he wanted to go to Dignitas himself.

Charlotte Moore, BBC Commissioning Editor for Documentaries, said that assisted suicide was an "important topic of debate in the UK.

"This is a chance for the BBC Two audience to follow Sir Terry as he wrestles with the difficult issues that many across Britain are also faced with. I hope this sparks a constructive debate that people across the spectrum of opinion can engage in."

Meanwhile high-profile campaigners against any change in the law on assisted suicide have written to the BBC expressing their own concern over the corporation's editorial bias in this area.

Baroness Campbell of Surbiton, writing on behalf of campaigning group Not

Dead Yet UK, and Richard Hawkes. Chief Executive of Scope (the charity which publishes Disability Now) have sent letters to BBC Director-General Mark Thompson ahead of the Sir Terry Pratchett screening.

And speaking following the launch of a survey on assisted suicide commissioned by Scope. Richard Hawkes said: "Assisted suicide is a complex and emotional issue, and there are loud and passionate voices on both sides of the debate. But while high-profile lawyers,

doctors and celebrities such as Terry Pratchett and Sir Patrick Stewart grab the headlines, the views of the thousands of ordinary disabled people who could be affected by this issue are rarely listened to.

"Disabled people are already worried about people assuming their life isn't worth living or seeing them as a burden, and are genuinely concerned that a change in the law could increase pressure on them to end their life."

The BBC said it did not have a stance on assisted suicide, and that a Newsnight debate on the subject would be screened after the programme.

Supporters of assisted suicide said that attempting to silence the issue was "irresponsible" and risked driving it underground.

Sarah Wootton, Chief Executive of Dignity in Dving said: "People are taking desperate and dangerous decisions at the

end of their lives; travelling abroad to die or attempting to end their lives at home. often alone for fear of their loved ones facing prosecution.

"The situation we are in now is unacceptable, which is why Dignity in Dying campaigns for a change in the law to allow terminally ill, mentally competent adults the choice of an assisted death."

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## politics

## Tory quits in cuts protest



With signs of voter discontent over coalition policies, the Government's policy on cuts has led one disabled politician to review his position, says **Sunil Peck** 

disabled councillor has decided to step down in protest at Government plans to abolish Disability Living Allowance (DLA).

Ollie Flitcroft, a wheel-

chair-user, is one of the first Conservatives to criticize ministers publicly for targeting disabled people disproportionately with cuts.

Cllr. Flitcroft served as a Conservative member of

Barrow Borough Council since 2006. It remains to be seen what impact his protest has on Government policy.

According to Cllr. Flitcroft, the Government's claim that the application process for DLA requires self-assessment is "nonsense". He also said it was "ludicrous" for the Government to suggest that a wheelchair-user capable of propelling themselves short distances might not need a mobility component of DLA.

"Why does the Government want to spend a lot of money on reassessing every single claimant, some of whom have impairments that will not improve. I'm not suddenly going to be able to walk tomorrow, so why have I got to go through an assessment?"

Cllr. Flitcroft does say that the Government needs to clear the country's debts. But he says that ministers should look to bankers' bonuses and tax avoiders to recoup money.

"I think many disabled people will say we've been involved in a war in Iraq, we're engaged in a war in Afghanistan and now we're going into Libya.

"But my right to independence is being put at risk. How is that fair in a just society?"

Despite his anger, Cllr. Flitcroft has been pondering his position for months.

Although the decision was a hard one to take, he regrets that his decision to

stand down has left the UK with one fewer disabled councillor.

"I've enjoyed being a councillor and I've met many great people doing fantastic work.

"It wasn't a decision I made overnight. I thought to myself: can I stay a councillor and influence the

It looks like the policy on the mobility component of DLA for people in residential care is in chaos

Government? I came to the conclusion that I couldn't. and that I couldn't remain a Conservative councillor, given what they are planning to do."

It "flabbergasts" Cllr. Flitcroft that the decision to cut DLA is being presided over by David Cameron, because he had a disabled son.

He also describes the Conservative MP Paul Maynard as being "misquided" for toeing his party's line on DLA.

"We already know the cuts are having a detrimental

effect on disabled people. Instances of hate crime have risen and people are being pushed into poverty and isolation because of the cuts, and the changes to DLA will make it worse."

Cllr. Flitcroft says that he hopes his action will add to the pressure on government to rethink its plans to abolish DLA.

"They tried to sell off the forests and backed down

from that. It looks like the policy on the mobility component of DLA for people in residential care is in chaos, and I think they need to stop this rebranding of DLA and the planned reassessments of everyone.

"We need to look at how we apply DLA in a fairer way. Replacing it with personal independence payments isn't going to help anybody."

#### → Have your say

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## worldview

## From wrongs to rights



Rights advocate Melissa Miller describes how disabled people and their organisations have set about changing hearts and minds in this West African state

minata cycles into the dusty yard on her handbike. She has just turned 18 and finds herself alone, having recently arrived in the capital. She has nowhere to stay, no money, no job and is six months pregnant. As a child Aminata had been badly burnt and her lower limbs are now painfully infected. She is the first visitor to the newly opened drop-in

centre at Handicap Solidaire Burkina (HSB). Her voice is barely audible when she speaks, but if anyone suggests that she return to her village they are met with a steely resistance.

Several days later, we sit facing the director of a women's rights centre and hear the all too familiar words uttered: "We work with women, but not disabled women." An HSB colleague and I had spent

days accompanying Aminata to women's centres only to find ourselves stuck in this déjà vu scenario. We would point out the hypocrisy of this statement, protest and outline the rights enshrined in national and international law but to no avail; in the eyes of certain non-governmental organisations (NGOs) disabled women were simply not part of their female target group.

After much advocacy and weeks of phone calls up and down the power chain, Aminata is eventually offered a place in a centre for young mothers and receives the medical treatment she needs. However it has been no easy battle.

Structures created to alleviate poverty and promote the respect of human rights are often violating the very human rights they seek to promote. Many local and international NGOs are quilty of, at best, an ignorant oversight or, at worst, a flagrant abuse of human rights when they fail to include disabled people in their development programmes.

HSB is a local disabled people's organisation (DPO) that began life providing employment and sporting opportunities before taking on an advocacy role to address the root causes of disablist discrimination. For change to be sustainable. HSB sought to translate the rights outlined in national and international legislation into transformation on the ground through raising awareness at a community and institutional level. With a small budget and an

abundance of passion, HSB created a programme to promote the rights of disabled people in Burkina. This programme incorporated the opening of the first drop-in centre in Burkina offering support to disabled people and their families. the creation of a disability rights advocacy network and the delivery of disability rights training to national and international NGOs.

Within weeks of opening the drop-in centre, the HSB forecourt was filled with disabled children and adults. The centre adviser was accompanying people to schools, health centres and training courses to advocate for inclusive access. Many common problems were exposed on which the organisation and its new network collectively campaigned. HSB staff delivered training to an energised and mobilised network of 35 DPOs. As disabled people facing the same problems as those they were appealing to, our trainers understood the feelings of disempowerment.

The success of the disability rights awareness training with NGOs was less immediate. Many NGOs failed to see the relevance of disability rights to their work and refused to accept a meeting. The director of an NGO seeking to eliminate world hunger told us "we



**Many local and** international NGOs are guilty of, at best, an ignorant oversight or, at worst, a flagrant abuse of human rights when they fail to include disabled people in their development programmes

don't work with disabled people". This despite the reality that disabled people have less access to education and employment opportunities in Burkina and are therefore more likely to suffer from malnutrition. Unfortunately this was not an uncommon response.

Perhaps most disappointing is the disablist discrimination that occasionally emanates from international NGOs claiming to work on behalf of disabled people in developing countries. It is inexplicable that such NGOs have yet to adopt the social model of disability, internally at least. I accompanied my colleague to a meeting with the coordinator of a European organisation that financed inclusive education for disabled children. My colleague was told that she could not become the HSB representative because it would be too much hard work for a person with her disability. After complaining to the head office the decision was overturned but should we really need to engage in this battle with an organisation that is supposed to be promoting inclusion? The sad truth is that many NGOs are content to maintain the charity model whilst using the excuse that there are no qualified disabled people to fill the posts and simultaneously doing little to alter the status quo.

Despite the discouraging response, HSB persevered. In a country that is still largely dependent on international aid, it was

imperative that disability be mainstreamed in development cooperation. HSB saturated the development sector: whenever there was a consultation led by the government, civil society or international institutions, a HSB member was there asking the same question: "How are you involving disabled people?" HSB significantly increased their profile and gradually NGOs began to sign up for the training.

One particularly momentous step was the training delivered to a network of organisations supporting young women, many of whom had closed their doors on Aminata a few months prior.

To respond to the need for further training in rural areas where disabled people have fewer opportunities, HSB trained six disabled people who are currently delivering the disability rights programme to civil society organisations and local government in 45 provinces across Burkina. The programme has established an awareness of disability rights at a critical juncture when Burkina recently ratified the UN Convention on the Rights of People with Disabilities (UNCRPD) and disabled people felt empowered to advocate for change.

## one2watch

## I wanna be a billionaire...

He may not have made it on to this year's Sunday Times "Rich List", but, like Travis McCoy, property investor Patrick Souiljaert wants it "so frickin' bad", as he reveals quite dogmatically in response to our questions



#### What first attracted you to property investment?

I've always wanted a job working with people and numbers. I was really inspired by Rob Moore, co-founder of Progressive Property, who said at a networking event: "Four years ago I was 30 grand in debt; now I'm a multimillionaire!" I remember thinking, "If you can do it, then I can do it - and I'm not 30 grand in debt!"

#### What one thing do you want to achieve in your career?

To become a multimillionaire.

#### What do you most like about your job?

Only 1% of the population are property investors - and I'm in that 1%.

#### What do you like least about it?

Nothing - I love it!

#### How may people and prospective clients react to your disability?

I didn't realise how inspirational people would find me until I started networking in the property investment community. I'm blown away by it and find it very humbling.

#### What makes you angry? Ignorant people outside of

the property investment world, who don't know how to talk to me and treat me like I'm an idiot.

#### How would you improve things for disabled people if you were Prime Minister?

As disabled people are exempt from paying road

tax, I don't understand why we don't get any tax relief on petrol. I would cut out all of the tax on petrol.

#### Who is your favourite disabled person ever?

My only disabled friend, Martin Brewer, who had muscular dystrophy. We met at school in 1984 and remained friends until he died in 2005, aged 32. Martin was a real inspiration to me.

#### Do you have a special or hidden talent?

I've got the mindset of a billionaire and therefore I'm going to achieve every single thing I set my mind on.

#### What advice can you give for any disabled person wanting to get into property investment?

Find the one thing you've always wanted to do in life and just do it. Don't stop until you get there. When you believe it, you will achieve it!

#### → Who do you think is One to Watch?

Send us your nominations for likely lads and lasses who could answer our 10 questions. They can be rising stars in any field of entertainment, business, the media or beyond

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# Governing Improse

It's a unique view from a unique perspective. Ahead of publication of the third volume of his uncut Downing Street Diaries, Alastair Campbell, the man dubbed Tony Blair's king of spin talks to lan Macrae about the privilege and pressures of being inside Number 10

here's nothing new about a fascination with diaries and diarists. They give us history intravenously, Samuel Pepvs' account of the Great Fire of London has urgency and immediacy because it is contemporaneous. More recently Alan Clark gave us a blow-by-blow account of Margaret Thatcher's fall from the highest office.

But Alastair Campbell says that his account of life at the heart of the Blair Government has something extra.

"The big difference is that I'm right at the centre. It's very rare for a diary to be published literally from the centre and that's its strength."

Clark, a good friend of his was, says Campbell close to the centre but also frustrated because he was also always at a remove.

Journalists and political rivals have, over the years found many accusations to throw at Campbell. Some, lacking any subtlety use clumsy shorthand relating to his openly proclaimed mental health problems and call him plain "Bonkers". Others, drawing overt or covert historical parallels have called him the power behind the throne.

"First," he says, "I've long gone past worrying about what other people see or say about me. The reality is that, in a modern democracy, if you're the Prime Minister of a country like Britain, then you have people who support you. The idea that, in a modern media age, you're not going to have someone lifting part of the blame for you is ridiculous."

The publication and success of Hilary Mantel's Man Booker prizewinning novel, Wolf Hall which had as its central character. Thomas Cromwell - himself described as "Henry VIII's spin doctor", led to direct comparisons.

Campbell laughs, remembering that



the author herself once described her hero as "Alastair Campbell with an axe".

"They were very different times. It's true that I was involved as a political advisor rather than just a media advisor, but at the same time you can't compare the world of Thomas Cromwell with the modern world.

I've long gone past worrying about what other people see or say about me. The reality is that, in a modern democracy, if you're the Prime Minister of a country like Britain, then you have people who support you

"There are all sorts of principles of government which maybe always apply, but the job that I was doing did relate to a completely changed media environment and that's what I was there to help Tony Blair and his colleagues adapt to."

So did he see himself as being involved in actually running the country?

"No. I saw it as helping him to get elected and then helping him to take forward the changes on which he'd been elected with particular regard for communication and strategy which were a very big part of that."

But it can be difficult to keep a strategic focus when you are also required to fire fight crises, sometimes on a daily basis. Certainly in the months and years following New Labour's landslide election victory in 1997, the honeymoon was shorter than they might have hoped and the administration was overtaken by what Harold Macmillan once wanly referred to as "Events, those unforeseen, if not always unpredictable personal and political scandals and catastrophes".

The death of Princess Diana. controversy over political donations by Formula 1 boss Bernie Ecclestone, sexual scandal surrounding Welsh Secretary Ron Davies's "Moment of madness", Home Secretary Jack Straw's son being involved in news stories about cannabis, and Peter Mandelson's first fall from grace over a loan from Geoffrey Robinson. All created media frenzies which required Alastair Campbell's attention, energy and savvy.

"One of the reasons I was a bit of a control freak and trying to centralise was that you need to stay on top of the day-to-day while also needing to stay focussed on strategy. Being on top of events and the management of events is what allows you to be strategic. We did become more strategic as we went along, but, of course, as time goes on, we became less popular.

"You can see in the second volume that the power of events does consume an awful lot of energy and time."

#### livingnow

Defining the difference between electioneering and governing, Campbell reaches in one diary entry for the phrase coined by former New York City Governor, Mario Cuomo, "We campaign in poetry, we govern in prose". Nowadays it's so often quoted that it's become almost a cliché. But at the time it had real resonance in Number 10.

"The reason everyone quotes that now is that it's such a brilliant phrase and a brilliant description. When you're out on the campaign trail, anyone who's any good at it is really trying to get people to soar to the heights. And it is different in government.

"But then again, something like Northern Ireland, that was bloody hard prose that was really hard work. And yet, you get some of the poetry back into it when, for example, the Good Friday Agreement comes together.

"The other thing to keep in mind is that this is my diary not anybody else's and my mood does weave in and out of it and I am pretty down about most



Alastair blowing hot and cold again?

things. So I'm perhaps more likely to focus on some of the stuff that's a bit dark".

Something else which clearly emerges from the diaries is Campbell's almost constant irritation and irritability. He is pissed off for a lot of the time.

"I remember Tessa Jowell saying to me that I was a victim of my own success. I'd set up this command and control situation, and then, at the weekend, trying to get a bit of guiet time, everybody's phoning wanting to know the line on this or to tell me

they're doing that."

This brought pressure to bear, not only on Campbell himself, but on his partner, Fiona Millar and his relationships with his children. In addressing how he coped and went on coping, he kind of echoes Churchill's old dictum, "Keep buggering on".

"I think I probably just did. I was a bit of a workaholic, probably am still to some extent. I got better at delegating as time went on. Understanding you can delegate and still have control is important. I had a very good team, but the other thing I had was an ability, a capacity for hard work."

To a greater or lesser degree, Alastair Campbell's time at the heart of what came to be known as "The Blair project", was haunted by an event in 1986 which has shaped much of the rest of his life. At a Labour party conference which he was attending as a political journalist, he had a mental breakdown. He describes its impact.

"The reason why I sometimes say that my breakdown in '86 was the best thing that ever happened to me is because it's the thing which I use when I do feel a bit edgy. I always compare how I'm feeling with that."

In the first volume of the diaries, he describes how, returning to Scotland in 1994, it seemed to him that it all got very close to happening again. Other



In the corridors of power: Alastair with Tony Blair and Bill Clinton

**66 Something like Northern** Ireland, that was bloody hard prose that was really hard work. And yet, you get some of the poetry back into it when, for example, the Good Friday Agreement comes together

episodes of depression occasionally have an impact on his ability to do the job, but, like many people in that position, he has developed mechanisms for dealing with them.

"I would sometimes ask my deputy Godric Smith to do something for me, so in extremis, I'd admit to myself that I couldn't actually function in the way I was expected to.

"You find your own mechanisms,

and, actually, bizarrely - and this is probably really dangerous - I would throw myself into work even more because that was the only thing that would take my mind off it."

Finally, there is the question of Gordon Brown, once memorably described by Campbell as having "Psychological flaws". So did Blair's successor suffer from Campbell's absence?

"The books record that Gordon and L had our ups and downs, but at the same time I was always straight with him that once I'd left in 2003, I wasn't going back full time. I think that maybe he felt that therefore his operation wasn't as strong.

"But he's admitted himself that he underestimated how big the gap was between being Chancellor of the

Exchequer, and a very good one, and taking on the job of Prime Minister."

And are there any qualms about calling into question Brown's own mental health?

"There was a point when I was at the end of my tether with Gordon and with Charlie Whelan and I did sometimes go over the top.

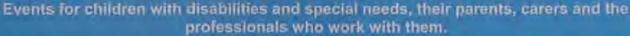
"But part of me says that there's no reason why, if people do have worries about their mental health, they shouldn't be completely open about it."

 The third volume of Alastair Campbell's diaries, Power and Responsibility is published in hardback in July along with the paperback of the second volume, Power and the People, both by Random House, Randomhouse, co.uk



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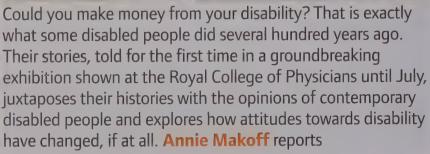












# Public Image Disability on show

as a sign of the devil. Much later, 18th century belief thought it was due to the mother's vivid imagination during pregnancy which caused birth defects. The majority of disabled people therefore tended to be society's write-offs and were either confined to institutions or left to die in poverty.

Yet, as the exhibition, *Re-framing Disability* demonstrates, not everyone accepted their fate: they wanted more from their lives.

Actor, playwright and focus group participant in the exhibition, Sophie Partridge says: "I was gobsmacked by the portraits we were shown. I assumed that anyone born hundreds of years ago with a disability would have been a write-off. Yet we were shown pictures of nicely dressed disabled people totally in control of their lives. I was really moved by it,

knowing there was a whole history that had gone before."

These disabled people made money by exhibiting themselves: the general public paid to stare and gawp either in private viewings or at touring "freak shows".

Although many people today feel uncomfortable with "freak shows", wheelchair-user Sophie believes that

#### It's not that I want 'positive representation' necessarily, I just want real representation

there is even now a fundamental power shift between the audience and the performer. In fact, one of the few freak shows still operating is the *Coney Island Freak Show* in New York.

Sophie, who also makes a living out of being stared at, although it's a different kind of staring – she is a

stage actress, says: "If people feel happy appearing in the shows then that's OK. It's like I said at the exhibition: if you're going to get stared at, you might as well get paid for it. Besides, performers turn freak shows on its head now. They get what they want out of it these days."

Actor Tim Gebbels (*Cast Offs*, Channel 4, 2010) believes that although there have been "deep fundamental changes" in attitudes towards disability, the desire to "look and gawp" is just as strong.

"People who go and watch such shows today have the same instincts and curiosities as audiences one or two hundred years ago," he says. "I don't necessarily think that is a bad thing, it's human nature to be curious."

However, it's one thing to attract staring onstage but quite another to attract unsolicited staring offstage. One is actively encouraged, the other isn't.

"Some people are persistently rude"
Sophie says. "They just won't stop
staring. I try not to be angry because I
don't want to come across as the 'bitter
crip'. As a disabled person you are
walking a very fine line all the time."

Disabled journalist Lee Ridley agrees. "I tend to ignore it up to a point, but if they start whispering and laughing, I tell them where to go with my hands. Sometimes I just can't help it – they can't expect to take the piss out of me and for me to just take it. I feel like I have to respond."

For some disabled people, particularly those with hidden disabilities, unsolicited staring is the least of their problems. Blogger and disability rights activist Sue Marsh has a rare form of Crohn's disease. On a particularly bad day, Sue has her medications switched over to injection because she is unable to take things orally.

"Because I am so thin and I look malnourished, people come up to me and say, 'eat a fucking doughnut,'" she says. "I heard one mother say to her child in the supermarket that if she didn't eat more she'd end up looking like me."

Sue recalls a time – several days after one of her many operations – when she asked a builder to move his van from a disabled parking space. "He absolutely candled me. The phrase was: 'What's wrong with you then, you fucking Belsen refugee bitch?'"

Sue attributes the regular abuse she experiences to the fact that people find it hard to accept that illness and disability can affect a young-looking woman with no obvious disfigurements, who is seemingly able to walk.

"Nature doesn't want us to accept that," she explains. "It's much easier for people to find a reason why I could be making it up, than it could be to accept that it could happen to their niece or child. In that way, I don't



Clockwise from top left: Lee Ridley; Sophie Partridge; Tim Gebbels and Sue Marsh

think people's attitudes have changed all that much."

Tim Gebbels has had a different experience. Blind since birth, he believes that those with visual impairments are more readily accepted by society because the disability is obvious to outsiders.

"People with hidden impairments do have a great problem being understood and being perceived correctly," he says. "The big issue for them is how to explain their needs and make people understand. With blind people, everyone says 'ah yes, you are severely disabled, have a big fat benefit cheque."

This is something that Lee also relates to, although in Lee's case society tends to notice his disability a bit too much. "There is definitely a lack of understanding about disability, especially cerebral palsy, and I think it is this ignorance that causes half of the problems," he says. "Yes I am disabled but I'm not stupid, and I'm not deaf – I can hear what people are saying."

On top of the seemingly intrusive attitudes which don't seem to have changed since previous centuries, Sue is concerned that these attitudes could take a more sinister turn. Citing politicians like George Osborne and Chris Grayling who use inflammatory language such as "scroungers mugging the state" she says: "It's become almost state endorsed: there is the sense that it is now OK to start speaking like this, it is OK to start judging disabled people. We are portrayed as a burden on the state."

Set against a background of benefits shake-up and media spin, Sue Marsh believes control and independence are being taken from disabled people under the guise of "savings". Added to that the concern that very few politicians are standing up for the disabled community – therefore disenfranchising a significant proportion of the electorate – the picture Sue paints is particularly frightening.

## He absolutely candled me. The phrase was: 'What's wrong with you then, you fucking Belsen refugee bitch?'

"If you are the sort of person who easily believes what politicians tell you – and why wouldn't you if everyone is saying it? – and you believed that disabled people are a burden on society and shouldn't be supported by the state, how far does that go? The line is very, very close."

Tim, who also hotly disputes the "nation of scroungers" beliefs, describing them as "cobblers", does not agree with Sue's concerns. When it comes to peoples' attitudes about disability, he just isn't fussed.

"I don't care if society sees me as a burden," he says. "As long as I have talking buses, or I'm not charged extra for having a guide dog in a hotel room, up yours. They can think I'm a burden if they like, it's a free country. In that way, things have changed for the better."

Tim believes it's all about compliance. As long as there are laws forcing people to adhere to accessibility policies and laws preventing people from restricting access or refusing entry on the basis of a disability, it doesn't matter to him.

"I don't mind if I go into a shop with my guide dog and the owner is really furious because they have to let me in. I don't care, as long as they serve me. I don't care, as long as things are done that improve lives."

It is a principle that works across the board – in navigating transport systems, in applying for jobs, to booking holidays, to being cast on a

television programme. "It's about normality," says Tim. "When it becomes normal to walk into a café and there are people doing sign language or there are people in wheelchairs, the more that happens, the more people go 'so what?' That is habituation and it's the same concept with television."

Certainly in the last five years there have been some improvements towards disability on television. More disabled people are appearing in soaps (Peter Mitchell in Hollyoaks or Andy Walker in Emmerdale, for example) and there are a lot more programmes about disability issues than there were. Yet Sophie Partridge is of the opinion that programme makers still haven't got the balance right: the portrayal of disability is one of extremes. Disabled people are either vulnerable and

incapable or brave and wheeling up mountains in their chairs.

"You only have media stereotypes to go on," Sophie says. "It's not that I want 'positive representation' necessarily, I just want real representation. I have this real bugbear with wanting to tell it like it is. I don't want to be anyone's hero. I iust want to be able to live my life."

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## yourviews

#### **Assisting is no crime**

I get annoyed with people who sit in judgement on others. Why should anyone be afraid of assisted dying?

My wife and I have talked about this subject over the years, and listened to all the arguments. We came to the decision some time ago that were the law to be changed and were it not illegal for one of us to assist the other in a dignified death, each of us would be able to do so.

Nearly two years ago, on her 60th birthday, my wife was diagnosed with stage-4 ovarian cancer. After months of chemotherapy she was told that nothing could be done and it was terminal.

Since then she has had no quality of life whatsoever. She can do nothing and go nowhere. She was told in late 2009 that she would not make it to Christmas, and definitely not to her 61st birthday. In spite of that, she is still with me.

She wants it all over, and although it breaks my heart, I have to agree with her.

If the law were changed I would assist her to die. I would do it with a broken heart but I would do it, because I love her with all my heart, and do not want her to continue to suffer.

With proper safeguards in place, there would be no fear surrounding assisted

dying. Unless the person concerned had actually requested an assisted death, any act leading to a death would still be murder.

I've watched our doctors and nurses at the hospital over the past months and never have I ever seen any patient neglected. In fact, the opposite. The more frail and terminally ill the patient is, the more care is lavished upon them.

Our doctors and nurses obviously want to keep patients alive, rather than lead them to an early death.

It is not the doctors and nurses who let patients down; it's the system. Every area in patient treatment is understaffed, staff are run off their feet, and yet our governments (all of them) keep cutting NHS funding.

Across-the-board cuts affect the vulnerable, the elderly, the disabled and the working class. That's something none of the millionaires in the Cabinet (18 at the moment, according to *The Times*) can have any experience of.

Let's be sensible about assisted death (not suicide), change the law and put in the necessary safeguards, and let us not be soft on anyone who breaks these safeguards.

Les Harrison, by email



#### **European Disability Forum falsely accused**

In response to last month's letter "European Disability Forum [EDF] fails us" (Disability Now, May 2011), we have worked with the EDF and are disappointed with what the letter-writer has to say.

We agree that in some countries, institutions are unfortunately being funded by European funds. That is something that is permitted by European law but EDF does not support this, and is campaigning for the law to be changed before the next tranche of funding from 2013–20.

The European Network for Independent living (ENIL) does not support the development of institutions as implied in the letter. EDF has worked along with ENIL and other European disability NGOs such as Inclusion Europe, Mental Health Europe, and Autism Europe, trying to develop community-based structures to replace institutions.

As the leading organisation for independent living, ENIL has always campaigned against institutions. Nonetheless, it is essential that EDF exists as it is very active within the European Commission and is able to react when an issue arises or when the Commission needs advice.

Without EDF we would not have achieved access to aeroplanes (as recently publicised in the story of the UN Special Rapporteur on disability being denied access to a Swissair plane), for example.

In the current economic climate, we believe EDF has an important role to play.

John Evans OBE and Jane Hunt, by email

#### Make all bays equal

Isn't Alice Pike missing the point about disabled parking bays? (See "Ask the Experts", Disability Now, May 2011.) I'm a wheelchair-user and L think that if Alice means she doesn't mind nondisabled people using disabled bays, why not make all bays for disabled people and non-disabled people alike wider? At least if they were wider, wheelchair-users would have enough space to manoeuvre in and out. Paul Butt, by email

#### **Getting medieval**

The Government's plans for Disability Living Allowance (DLA) are making disability sound more and more feudal. Soon, we'll start being called "handicapped" again, as we all stand outside Government buildings, cap in hand, begging for alms! What happens to Motability if PIP (Personal Independence Payments) provision ends automatically when we retire or turn 65? Do we all have to give our cars back and hide behind closed doors so we don't embarrass the Government? Brenda Hawkyard, by

email



#### **Government's heavy hand is bullying**

Can anyone explain to me the Government's obsession with disabled people?

From Thatcher to Cameron, they have all tried to bully disabled people. Why don't they bully the banks to get our money back and leave us alone?

By all means sort out the scroungers but please leave the rest of us alone. How would they like it if we died and it said on our gravestones "Could not get help from the Government"?

How can these people

sleep at night knowing that they are killing us slowly?

Why can't they pick on something else instead, and leave us alone?

Neil Preston, by email

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## andyrickell

## Reform and the assessment process



In creating new assessment procedures for reformed benefits, the Government, argues Andy Rickell should be sure they are not alienating and disempowering for disabled people

e should be thankful that after George Osborne said the reform of Disability Living Allowance (DLA) would include a "medical assessment", there was a rapid distancing by government from the term "medical" or its implications - they are learning!

Historically the state uses the clinical and social care professions to assess whether disabled people are "disabled" enough to receive state support – cash benefits or in-kind. This is based on several deepseated assumptions – that disability is essentially an impairment issue that must be evaluated by people with professional expertise; that disabled people cannot be trusted to represent their needs accurately or intelligently; that such support is provided because you cannot do something rather than as an enabler to independence; that each bit of support requires an appropriate and different

assessment, and that protecting the taxpaver is more important than people's welfare.

To the voting taxpayer, the politician knows that "medicals" play to the populist idea of catching out the "scroungers". To the disabled person, who recognises the assumptions behind the "medical", it is understandable they fear such "assessments" as the unreasonable imposition of a disempowering process. Coupled with recent bad experiences of the Work Capability Assessment, "assessment" frightens disabled people, with good cause. This culture must be overcome, starting with the new DLA assessment.

It is absolutely reasonable to have some fair means of evaluating that a claimant meets the democratically agreed criteria for receiving a state benefit - otherwise non-disabled people could claim disability support without challenge! Equally it is absolutely reasonable that the disabled citizen

should be provided with the most accessible and empowering process that gets them the benefits and state support the law allows, simply and quickly.

The obvious solution is to create a single assessment process for all of the support and benefits available to a disabled person, and one that the state helps the individual to

The disabled citizen should be provided with the most accessible and empowering process that gets them the benefits and state support the law allows. simply and quickly

navigate. In the meantime any new assessment, like for DLA's replacement, must match those best design principles. Disabled experts and activists would be an excellent group to be involved in the design, oversight and review of

such an assessment process.

Any actual "assessment" meeting must be done positively, encouraging and supporting the disabled claimant to best represent their case in an empowering setting, and the claimant be given the chance to challenge and give evidence that may refute any negative evaluations an assessor might make. Furthermore, the assessors should be highly trained in engaging with disabled people and understanding the diversity of issues faced by us. Indeed I believe that disabled people ourselves would make very effective assessors - our personal experience gives us a competitive advantage. And the assessor should not be the person who makes the state's decision - so that the assessor's job is only to get the facts that result in an accurate and fair decision and any evaluation of assessor effectiveness should be on this basis alone.

A good and fair process will get disabled people's support. Otherwise welfare reform will feel like the same poor system.

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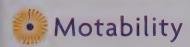
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Psychologist with psychosexual therapy experience

#### Legal **DOUGLAS JOY**

Senior solicitor at the Disability Law Service

#### **Benefits and Debt** Citizens Advice Bureau and Disability Alliance

#### **Technology and Internet** LÉONIE WATSON

Works with digital consultancy Nomensa

#### **Specialist Equipment** JOHN MANDRAK

Disability journalist and DLF helpline adviser

#### Travel **ANDY WRIGHT**

MD of Accessible Travel, specialist tour operator

#### **Money Management DAVID CLARKE**

Senior partner with Clydesdale Bank

#### Access and Environment **AGNES FLETCHER**

Disability trainer and consultant

#### **Property** KATE SHEEHAN

Director, OT Practice, with special interest in housing

#### **Motoring and Transport HELEN DOLPHIN**

A director of Disabled Motoring UK (formerly Mobilise)

## They don't mind letting me die

I am an 80-year-old hospital patient. Early in March I had an appointment and was asked to hold the folder containing my notes. In my

folder I noticed a vellow sheet saying "Do not resuscitate," in big black letters. No one had talked to me about this. I am now very unhappy and nervous. I have a lovely husband and a good life. I trust my faith as a Christian will see me through but I'm worried. Name and address supplied



Agnes Fletcher says: This is an outrageous

abuse of trust, which goes against the clearly-stated guidance of the British Medical Association and the Royal College of Nursing.

A "Do Not Resuscitate" (DNR) order on a patient's file means that a doctor is not required to resuscitate a patient if the heart stops.

Used appropriately, DNRs prevent people suffering pointlessly from the effects that resuscitation can cause, such as broken ribs. other fractures, a ruptured spleen or brain damage.

The usual circumstances in which it is appropriate not to resuscitate are:

- · when it will not restart the heart or breathing
- · when there is no benefit to the patient
- · when the benefits are outweighed by the burdens.

The last of these factors. in particular, can be highly subjective and this is where problems can arise. The medical profession is not famed for its understanding



that a positive life can still be led with substantial impairments.

In spite of that, quidelines issued by the British Medical Association and the Royal College of Nursing say that DNRs should only be issued after discussion with

patients or their family. Although it may be difficult to have such discussions with patients and their relatives about whether to revive someone or not. doctors accept that this is no reason why discussions should not take place.

In the UK, NHS Trusts must ensure that:

- · an agreed resuscitation policy that respects patients' rights is in place
- · a non-executive director is identified to oversee implementation of policy
- · the policy is readily available to patients, families and carers
- the policy is audited and regularly monitored.

The clear quidelines on DNRs had to be firmly restated in 2009 after a number of seemingly healthy patients discovered they had DNR orders written in their medical notes without consultation with them or their relatives.

You should tell as many people as possible about what you have discovered, and complain both to the manager of the ward that vou are on and to the hospital trust through its usual complaints mechanisms.

You should state clearly that you do wish to be resuscitated, if that is your wish. Others in your position should do the same.

If you are in hospital and have any concerns about this issue, you should make your wish to be resuscitated clear and ask for it to be recorded in your medical files. Age UK is very concerned about this issue and may be able to offer further support.

# What benefits can my hole-in-the-heart son get?

We are currently awaiting an appeal to see if our eightmonth-old son qualifies for DLA personal care. Our son has a hole in his heart and has narrowing arteries. He is on propranolol three times a day to keep his heart steady and is waiting to see a surgeon about open-heart surgery, but could you tell us if we are entitled to anything else? My partner works full-time on a minimum wage. We get child tax credits, working tax credits and child benefit. Are we entitled to help with transport or anything else? **Cassie Symms, Sheffield** 



Ken Butler of **Disability** Alliance replies:

I am very sorry to hear of your baby son's serious ill health. One of my sons had an operation soon after birth due to a heart defect and I can appreciate the great worry and concern you and your partner must be experiencing.

Disability Living Allowance (DLA) is a nonmeans tested benefit that has two parts: a "mobility" component and a "care" component.

While there is no lower age limit for DLA, a mobility component to help with transport costs is not payable until a child is at least aged three years old.

There is an extra "disability test" for children. This establishes that a child has care or watching-over needs "substantially in excess" of usual children of their age. It can often be difficult to demonstrate this in the case of infants. It would therefore be very useful if your son's medical team could set out for you the degree and level of such extra care and/or watching over that your son will need and for how long this might continue.

An extra "disabled child element" is payable within child tax credit if a child (or young person) receives either the mobility or care component at any rate (or if they are registered as blind). This is worth £2,800 per year for those entitled to maximum child tax credit.

If a child receives either the higher care component of DLA (due to both day and night time needs), then an additional "severely disabled child element" is payable within child tax credit. This is worth £1,300 per year for those entitled to maximum child tax credit.

In addition, if a child is awarded either the middle or higher rate of the DLA care component then you can claim carer's allowance for looking after him or her. This is paid at £53.90 per week and is not means tested (although it is not possible to receive it if you have earnings of more than £100 per week).

You should seek help from a local advice centre to see if it might support your son's DLA appeal and advise you if you might also be eligible for help with things like rent and council tax or NHS charges.

· A fact-sheet on finding a local advice centre is available: disability alliance.org/fact.htm

#### → If you have a question for our panel

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# pete'splace

## Death doctors and DNR



As we hear yet again from a patient who has seen the instruction "Do Not Resuscitate" scrawled on her notes. Peter White goes to the heart of what causes such dangerous presumption

t's the stuff of idle banter at smart medical dinnerparties, or gossip in the sluice-room: those amusing little acronyms scribbled in the margins of patients' notes. I don't spend much time in sluice-rooms and am never invited to smart medical dinner-parties, so I forget most of them; but you know the kind of thing: Ch: Confirmed hypochondriac; Mm: Moaning Minnie; Aob: Awkward old bastard! Worth a quick snigger, perhaps, until you get to that insidious Dnr: Do not resuscitate, which can prematurely snuff out a life at the stroke of a pen. I'd like to add one of my own: Yas: You arrogant sods.

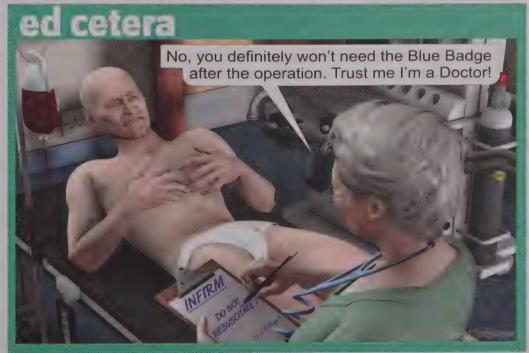
But the arrogance of the medical profession is a path much travelled in these columns, so I'd like to explore why this continues to happen, against the background of repeated assurances that it won't.

There are people who have figured out how to live with the consequences of a condition or impairment; physical knocks, pain, feeling unwell, being ignored and under-estimated and, yes, the risk of death if

something goes wrong. I think people who do this on a day-to-day basis, and who have built tolerance of it into their lifestyles, are beyond the comprehension of doctors, who are often used to dealing with people who regard perfect health as a constitutional right, and who often believe that doctors have godlike powers to deliver this: a belief which rubs off on the doctors themselves. My own blindness, with few other medical consequences, doesn't

qualify me for the group of disabled people I'm talking about, I know, but I get a sense of it every time I walk to work, bouncing off trees and newly-erected scaffolding, tripping up or down kerbs, or trying to effect a dodgy road crossing. These incidents aren't life or death to me - except for the efforts of the odd lorrydriver - but I know that when the public see it they are horrified, and many feel an overpowering need to intercede, and stop it happening. The idea that it might just be a regular part of my life that I've come to accept is beyond them, and doctors are no different: apart from the crucial fact that they think they have the right to an opinion on the

matter. And so it is with those whose disabilities place them in mortal danger, and who therefore need medical intervention to help them. The problem: that doctors, looking at the rest of the medical notes, somehow can't envisage that this is a life which has been crafted and sustained around the tolerance of risk, and the continued wish to go on exercising it. I've not even mentioned the obvious right to consultation, the right to self-determination, the right to respect: those should really go without saying. What would perhaps be more fundamental is the understanding that no one, not even doctors, have the knowledge to understand the value of another life.





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choosing a wheelchair car" says Ron Heaton, who has almost 20 years experience ensuring that customers' wishes are met. "We've just had an accountant return to order his new car as his original Brotherwood conversion is 15 years old" he continues "but nearly every week we have families turning up at the factory who have bought the wrong vehicle from another company, often because it was cheaper."

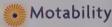
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## guestcolumn



## Loud echoes of past errors

In examining the current welfare reform agenda, Jim Elder-Woodward has spotted the continuance of past trends in current policy

ver the last decade or so, when New Labour was in power, there has been at least one welfare reform policy document or act every three or so years. However, I have noticed that the welfare reform objectives of the present Condem Government seem to have much in common with those of the previous New Labour administration.

First, there is the policy line of welfare reduction; of excluding people's eligibility for welfare by narrowing the goal posts. Both New Labour and the Condem Government stated they wanted to "simplify" the system, when they really meant they wanted to exclude people from additional supplements to benefits, or deny others access to benefits altogether.

But perhaps the most striking common policy direction is that of contracting out state

provision of welfare. New Labour's Welfare Reform Act of 2008 enabled benefits administration to be contracted out to private companies. These firms were to be paid extra bonuses according to their success in placing claimants in employment.

In 2009 New Labour gave a private company, A4E, £800m to run their "Flexible New Deal Scheme", with bonuses provided according to the number of unemployed people for whom they found jobs; jobs which they managed to keep for more than six months.

A4E followed a policy of "tough love" in their efforts to get unemployed people back into the labour market. The company told their clients they would not hesitate to take action to suspend their benefits if they did not receive their full co-operation. Their goal, through a process of bullying and counselling,

was to get long-term unemployed people into identified posts, most of which were low-paid and without any career structure.

This system of contracting out employment services to the private sector on a payment by result basis is also the policy the present Government is pursuing. But instead of providing upfront funding they are using the savings from moving people from Incapacity Benefit (IB) to Jobseeker's Allowance (JSA) to pay these companies by their results, so there is no "upfront" money being provided to find these people jobs this time.

Now we have the infamous private French company ATOS reassessing recipients of Incapacity Benefit being paid

depending on the number "assess" for Employment Support Allowance.

The potentially bogus nature of this assessment has been highlighted by the case of an ATOS employee who left the company on health grounds, but when she was "assessed" by the same company was found suitable for employment so was placed on the Jobseekers Allowance, rather than the Employment Support Allowance for those who are considered not to be "job ready".

Unfortunately, public pressure has not much influenced the Government's commitment to retain the company ATOS and its discredited assessment process, despite a highly critical parliamentary inquiry.

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# upclose&personal

# Moving out of Little League

n 10 March, 1997 I was diagnosed with multiple sclerosis (MS). It just happened to be my wife's 37th birthday.

About a week later I received a phone call from Little League, because I had applied to coach my sons (see photo). I was overjoyed vet cautious. It was what I wanted, but I wasn't sure if I could physically handle it. At the time, I was walking with an unbalanced and awkward gait. I wanted to keep my MS diagnosis private, but then again, I didn't want people to think I was a drunk either, since I walked like one.

So I fessed up and told the guy about my diagnosis. He was taken aback by it, but still accepted me. This gave me a wonderful opportunity, something I had time to do because I owned my own business and had enough flexibility to put time and energy into coaching.

Coaching Little League is the most rewarding and worthwhile experience by far of all the things I've done in my life! I found it very gratifying to show kids the basics and mechanics of baseball and the funda-



Aspiring American children's author Tony Evangelista writes about how frustrations over coaching his son Joey at baseball led him to write a book exploring issues of play and relationships

mentals of team play. It was tiring and challenging, without a doubt, but well worth the effort. I wouldn't have traded it for anything.

A few times one of the eight-year-olds said to me, "Why do you walk funny?" Instead of taking the

opportunity to explain, I got riled up and ignored him, leaving it to his father to take him aside and talk to him. That wasn't so good. Another time I was at first base when one kid was so happy to have won that he hugged my legs. I lost

my balance and he ended up falling on top of me. It was a little embarrassing but we got up laughing.

The following year I didn't coach. I started walking with a cane and had to get a nine-to-five job, which unfortunately brought my Little League coaching days to an end.

Subsequently, I found it more difficult just to go see the kids pitch on Saturdays. I was now confined to a wheelchair, and between the transportation and the physical struggle, it was too much for me.

It was disheartening not to see the boys' competitive talents develop. Then one of them, Joey, developed problems with his ankles. and with that his baseball future came to an end.

Fortunately my kids survived but as we all grew up, our formerly tight relationship suffered some alienation and distance.

That experience inspired me to create an illustrated children's book looking at the joys and frustrations of play from both sides of the disabled parent/child relationship.

· Tony Evangelista is hoping to find a publisher for his book Cartoon Boy





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've attended many Naidexes (what exactly is the plural of Naidex?) over the years, but I don't think I could describe it as a stylish exhibition.

As I wandered around the vast hall at the NEC, I realized how wrong I was. Everywhere I looked things that were once utilitarian were now cool, stylish and even sexv. Even as I wheeled through the entrance I was met by a huge brushed metal wheelchair lift by a company called Terry, that looked like it had been stolen from the Death Star rather than an institution. Chair lifts had never looked like this before. The next stand that caught my eye was Cape Wild, which make all-weather clothing for wheelchair-users, with a jacket that is cut especially for us wheelie types and a cool leg fleece that is a replacement for the tartan car blanket. Most interesting to me as I have just taken up stargazing, which means I have to sit up all night in the open air staring at the sky while my legs freeze.

Then I stopped in my tracks. Did my eyes deceive me? There on the Monarch Mobility stand stood a row of mobility scooters that were unlike any other. In bright pink, ice white and metallic blue, their Voque scooter looked more like a row of motorbikes. One of the guys on the stand informed me that they even do custom paint jobs, so one with flames down the side and a skull mounted on the front was easy to do. Still reeling from the shock of cool mobility scooters, I stumbled onto the Recare stand. This was jampacked with stylish, cool stuff. It was the massive all terrain tyres on huge wheelchair wheels that I noticed first, but this stand was so full that my head spun. They had the amazing Trekinetic and the Colour wheels but something that really appealed was the backpack bags made for wheelchairs made in ultra cool materials, like UV pink and



# Chairs, scooters, stairs and style

Going to Naidex 2011, Mik Scarlet's hopes of finding cool were not high. But this year's show pushed more style buttons than he thought it ever could

green metallic PVC, camouflage and Union Jack.

The hits of the show for me were the stair lift by Lift Able that was fitted to a spiral staircase (that was so cool it made me swear out loud, much to the pleasure of the guys on the stand) and the Sport

Rider scooter, by Drive Medical, that was more like the Harley Davidson ridden by The Terminator than a scooter. I know my mates at the National Association of Bikers with a Disability will love it.

Overloaded with how cool everything was. I ventured to the Stannah stand.



Top to bottom: Lift Able's spiral staircase; **Drive Medical scooter; Tomcat Trikes** 











Top to bottom: Monarch Mobility scooters; Bathex rails; Colour wheels

By now I was expecting great things. Stannah is a name that is kind of associated with being old, yet as soon as I saw the Active walking frame I knew that this was no longer true. They had designed a walker that would cope with all types of terrain, thanks to its huge wheels, and had a large seat for taking a rest while looking stylish. The new stair lift also fitted this new direction. OK, stair lifts have a job to do first, but this combines style with function. I asked Jon Stannah if he felt that style was becoming more important for disabled people?

"No, style has always been

important," he says. "What has changed is the fact that, as markets have developed, more manufacturers and suppliers have become prepared to invest in design."

So as I celebrate my 30th year as a wheelchair-user, I can see that the next 30 years will be filled with a much cooler choice of aids and adaptations. The only drawback is I'll need deeper pockets.

#### **COOL STUFFS**

Terry Lifts - terrylifts.co.uk Cape Wild - www.capewild.com

Monarch Mobility monarchmobility.com

Recare - recare.co.uk

Trekinetic - trekinetic.co.uk

N&C Phlexicare - www.phlexicare.com

Drive Sport Rider - drivemedical.co.uk

Lift Able – liftable co.uk

Stannah - stannahstairlifts co.uk

Forta All Terrain Wheelchair gelovationseurope.com

Tomcat Pedal Trike for all abilities tomcat.org

Ultra cool canes and walking sticks - classiccanes.co.uk

Handrails and grab rails in a rainbow of colours - bathex.co.uk

Excellent Systems – modular ramp system in cool colours - ramps.co.uk



If your expectations of a trip to Transylvania involve flapping wings, smouldering eyes, fangs, garlic and empty mirrors, Annie Makoff says think again and take a fresh look

tepping for the first time onto Romanian soil in the capital city of Bucharest was like entering a real life (and bitterly cold) Narnia. With temperatures -24 degrees, there was so much snow and ice that every vehicle on the road sported an icicle border around the car's body. I'd assumed it was the latest must-have in Romanian car accessories.

Travelling alone as a disabled woman to volunteer for six weeks on an expat magazine deep in the Transylvanian Mountains wasn't exactly most people's idea of fun. But I never have been one to follow the status quo. Booking the trip was one of the best impulsive decisions I've ever made.

Due to Romania's turbulent history during the Ceausescu regime, tourists were non-existent. People tended to wear similar clothes, speak about neutral, mundane things, visit the same places - anything so they didn't stand out and arouse suspicion from the regime. So even 30 years on, the novelty of seeing someone non-Romanian still has not worn off.

Although it can be disconcerting to

#### Did you know?

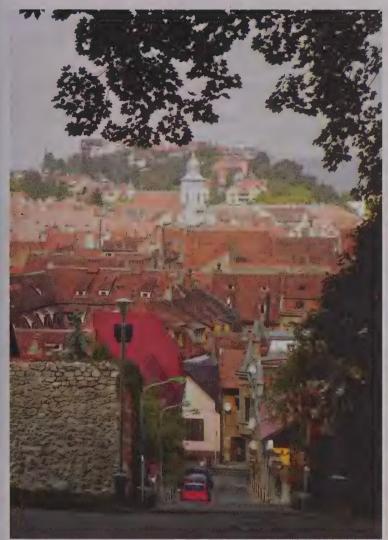
Brasov was also known as Kronstadt (in German) and Corona (Medieval Latin) when it was inhabited by the Transylvanian Saxons.

be stared at so crudely, it is not seen as rude in Romania. It is more of a curiosity.

And oddly, even though a disabled Romanian is usually ignored, a disabled tourist is regarded with awe.

Children in the orphanage I visited were fascinated with my disabilities. They could not believe that not only was I able to travel but that I didn't live in hospital (or on the street, for that matter).

Even as a woman traveller I was unusual. Whilst most women in urban Romania work, women's independence isn't as widespread as it is elsewhere. So as a disabled woman travelling alone for the most part, I must have come across







Opposite: Brasov's main square, Piata Stafului. Clockwise from top: A Brasov lane on the way up Mount Tampa; Prejmer Fortified Church; view from Mount Tampa; a typical Brasov street; Mount Tampa, sporting the famous Brasov sign.







Bran Castle - wrongly connected with Vlad the Impaler

as quite an oddity.

Once the initial culture shock wore off during my first visit, I began to see a different side to the country, one not often portrayed by Western media. It is this side of Romania that still stays with me. It is why I yearn to go back, why I've spent hours trawling online to find Romanian restaurants in London. or looking for local shops selling Romanian produce.

It is impossible to sum up in a few words why Romania has such a profound affect on me. Perhaps it's the relatively undiscovered hidden gems like Brasov or Sighisoara, that anywhere else in Europe would be swamped with coachloads of tourists. Perhaps it's the various Romanian customs like the first day of Spring on March 1st, known as Martisorî, where friends and family exchange "lucky charms" and bunches of snowdrops.

Or perhaps it's the incredible range of food places: cafés, bistros and restaurants serving a huge array of cuisines at incredibly cheap prices. (Cheap for us Brits, anyway).

Many restaurants often have local folk musicians and dancers clad in traditional costume, so it is always quite an occasion eating out in Romania, and not just for the culinary experience.

Although Romanian cuisine has been highly influenced by other nationalities such as Hungary and Turkey, it is still very much a unique mix of warming stews and soups, stuffed vine leaves or cabbage leaves with rice and mince (known as Sarmale) and polenta-based dishes.

Polenta, made from boiled cornmeal (not as vile as it sounds!) used to be the staple diet for Romanian peasants, often as a bread substitute. Now a

delicacy, it can be enjoyed as a side dish with sour cream and cheese.

Meat (particularly pork) is essential to the Romanian diet so vegetarians aren't catered for particularly well. And fruit addicts beware: because fruit is so expensive in Romania it can be hard to come by, especially in remoter areas.

I returned to Romania with my partner in the autumn of 2010 to spend a week in the chaotic capital city of Bucharest and a week in beautiful Brasov. But it was Brasov I was excited about returning to.

Brasov (pronounced Bra-shov) in Transylvania, nestled at the foot of the Carpathian Mountains, is a three hours train ride from Bucharest. The train journey on the latter part of the line, once you have moved away from the architectural legacy of Communism near the capital, is spectacular - you

#### Did you know?

According to local legend, when the Pied Piper of Hamelin led the children into the mountain, they emerged at the other side into Brasov.

travel right through mist-shrouded mountains.

A Saxon settlement dating back to the 1200s, it is much the same today as it was then, albeit with a mish-mash of incredible buildings from different periods of time. It is a historian's paradise, especially in the old town where modern buildings are few and far between. Miraculously, much of Brasov seems to have survived the Ceausescu regime relatively unscathed.

In the summer, Brasov's popular square, Piata Stafului and its neighbouring pedestrian streets are alive with cafés and bars spilling out onto the cobbles. Even in the depths of winter, when you have to trudge knee-deep in snow, the cafés are still open (although there is no outside seating). You can sample some of Romania's most popular tea, Ceai de Fructe (fruit tea) or treat yourself to some scandalously luxurious ciocolata calda (hot chocolate).

Piata Stafului, with its fountain and town hall can even be easily located miles above from the area's cable car which takes visitors up Mount Tampa. Views of Brasov and the surrounding areas are spectacular, and you can even climb behind the famous Brasov lettering that shines proudly from the mountainside in a Hollywood mimic.

Brasov itself is home to several unique attractions such as the two watch towers Turnul Neagru – black tower - and Turnul Alba - white tower and the first Romanian school. It is

also home to one of Europe's narrowest streets, Strada Sforii which at 111cm wide makes for a bit of a squeeze.

Although there is enough in Brasov to keep you here for many a week, attractions in the surrounding areas (including the famous Bran Castle, reputed – wrongly – to be the home of Vlad the Impaler) are well worth a visit. but be aware that there is often no wheelchair access in these places.

And unless you fancy crawling up (or if you're me, slipping down) an icy slope with no railings, don't visit Bran Castle in winter, although the lack of tourists in the cold season mean you have the castle more or less to yourself.

Visiting one of the 300 Saxon fortified churches in Transylvania is a must. Out of the three I visited (Harman, Codlea and Preimer) it was Preimer, north east of Brasov, which is arguably, the most incredible.

First built in the 13th century and added to during the 15th and 16th centuries, Preimer Fortified Church, complete with a portcullis, is a

complex maze of interconnected rooms surrounding the church itself. During a siege, the entire village took refuge in these rooms, which included food stores and a school room. A 30-metre secret tunnel, with tinv windows to observe the enemy, runs around the inside of the rooms.

As strange as it may sound, Preimer summed up my various experiences of Romania with its amazing structure, unlike any other, and then the surprise discovery of the secret tunnel which added another dimension to the experience all over again.

Romania, or rather the areas I visited, is full of surprises. It's not a predictable country. You just have to accept it at face value. And maybe that's the beauty of it, accepting for instance that in Bucharest they understand what you mean when you ask for a kettle in your room, whereas in Brasov, the word "kettle", in either Romanian or English is met with blank stares. But kettle or not. I can't wait to return.

#### How to get there:

Arrive at Bucharest Otopeni Airport and take a taxi to the main train station (Cara de Nord). The train journey to Brasov takes around three hours and goes through spectacular scenery.

#### Don't miss:

Corona café Brasov, at the frent of a small, classy but very reasonably priced shopping mall. You can order from their vast range of hot drinks. while looking out from the arched windows at the beautiful Piata Stafului below.

Festival 39, Brasov, an eccentrically decorated bar on the main high street. with a 1920s thome, boasting spiral staircases, candles mounted on carved

body parts and figurines, and an impressive array of black and white photographs mounted on brick walls.

Sighispara, north west of Brasov. Several hours train journey from Brasov, Sighispara's medieval citadel was the alleged birthplace of Vlad the Impaler Unspoilt combled streets, tiny lanes, a castle and looming towers make for an unforgettable visit, even if the numerous references to Dracula are a little tacky at times.

Warning: Taxis often charge over the udds to unsuspecting lourists. Always go with taxis charging no more than 1.40 - 1.70 lei per km (prices are written on the door) and always ask the driver to switch the meter on!

## tried&tested

# About getting out and about

Typical, says Lucy Howard. You wait ages for an accessible travel guide and then two come along at once

he Rough Guide to Accessible Britain has been a choice addition to the popular and reliable worldwide Rough Guide series.

The latest edition includes the results of the Accessible Britain Awards 2010, with the Eden Project in Cornwall the outright winner of the Readers' Choice award. Another recent addition is a Family Days Out version. with reviews of over 75 venues, available free at accessiblequide.co.uk.

Hot on the Rough Guides' heels is the second Open Britain quide, published by Tourism for All. This "definitive travel quide to accessible Britain" carries some weight, as is emphasised by a demandled increase in the print run for its 2011 edition.

The quide is easy to use and navigate around, and has clear contents and quidelines on how the reviews for individual accommodation and venue options are categorised and rated, including a key to the symbols used. There is handy colour coding for each location around the UK, with sections on



where to stay, where to go and where to eat, along with contact details for tourist information centres in each area. Throughout the guide there are colourful, evecatching images, and large, clear, accessible print, so it is easy to read as well as nice to look at.

Open Britain features summaries of UK highlights and suggestions on what to see and do at the start of each section, so that you can see what you like the look of before delving deeper into the chapter and finding out more.

There is something for everyone here, whether you want to travel on a budget or have cash to splash, and

whether you want to indulge your penchant for history at Stonehenge in the South West or visit the new accessible Elizabethan garden at Kenilworth Castle in the East Midlands.

Both quides are well written and researched, and work quite well in tandem because the Rough Guide looks more at venues while Open Britain looks more at accommodation.

The Rough Guide, despite being smaller and lighter, has more content and goes into more detail, so it is the guide to go to for the bigger picture - as long as its density and mainly blackand-white images do not put you off.

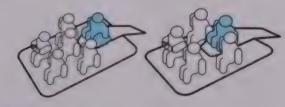
Open Britain 2011 is chunkier and features less content, but is worth the extra space and weight in your backpack, because of its accessibility and attractive layout. The trouble is, just reading it is so enjoyable that you are going to have to make an extra effort to tear yourself away and actually get out there and explore.

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## helendolphin

t the recent launch of the Blue Badge reforms Norman Baker MP, the Under-Secretary of State for Transport was keen to emphasise how accessible public transport now is for disabled people. Now I agree that things are definitely better, but I'd really like Mr Baker to accompany me on my next trip to to see just how "accessible" my trip really is!

The first leg of my journey is either by car or taxi. Car is much easier for me but this is only an option before 8.30am as after that the chance of finding a parking space is virtually impossible. Other rail users can use the nearby multi-storey car park but it's too far for me to walk and like many car parks it has barrier access which means it's totally inaccessible to me.

The next stage in my journey is boarding the train. Barriers have been installed at the station to stop people getting on without a ticket. and although this means that I can't go through them without assistance it does make securing help onto the train easier as I don't have to go around the station trying to find someone to put down the ramps. As I am a frequent traveller most of the rail workers at Norwich station know me and what help I need, which makes



Devoted driver Helen Dolphin decides for once to give public transport the once-over, for her as a disabled traveller on a regular journey from Norwich to London

getting on the train considerably easier.

The train operator running trains to and from London is National Express. There is space for a wheelchair-user and accessible toilets in first class. Not being a wheelchair-user but still requiring an accessible loo and having an assistance dog means I still travel in first class. Most passengers, I'm pleased to say, have no problem with my dog

Yancey and most of the time people don't even know she's there as she just sits under the table. However, it has amazed me how many people feel the need to prod her with their feet and I was told by one passenger that she shouldn't take up so much space - in first class! Where did he think I should put Yancey, in the overhead compartment?

Once I arrive I have to hope that there is someone there to meet me. Over the years this has improved considerably and the dread that I'm going to be left stranded on the train has somewhat diminished.

After getting off the train and fighting through the barriers with the rest of the passengers I usually make my way to the taxi rank, where 100% of the taxis are accessible for wheelchairusers. Unfortunately for me I still find them really hard to get into and rely on help to clamber in. However, on a recent journey I decided instead to have a go on the London Underground.

Armed with my map of accessible tube stations I set off. Knowing that I was going on the underground I decided to leave Yancey at home as I wasn't sure how good it would be for a dog. As it happened this was a decision I was glad I made. Sod's law meant the day I travelled there was a reduced service so every train was crammed full of people. If I'd had Yancey with me I think she would probably have been trodden on.

For this journey I was not on my own and I don't think I could have travelled independently. As I was standing up nobody realised how unsteady I am on my feet and I was banged and barged into like everybody else – I only remained upright by clinging to my companion

Nobody realised how unsteady I am on my feet and I was banged and barged into like everyone else - l only remained upright by clinging to my companion for dear life

for dear life. The step up onto the tube was more than I could do on my own and it was difficult to even get on with so many people.

I'm pleased to say when I

asked for the seat reserved for disabled people the person in it always gave it up.

With only 60 underground stations accessible for people with mobility problems I couldn't actually get to where I needed to, and so I had to get off several stations before my destination and hail a taxi.

I have to say I haven't braved the underground again but I think on a quieter day when the tubes are running properly it might not be so bad.

Disappointingly, of the 45 stations that former mayor



Ken Livingstone promised would be step-free by 2013, work on 22 has been deferred, while another two will only see partial improvements. Transport for London (TfL) blamed the decision on the economic

downturn and the financial impact of the collapse of Tube maintenance company, Metronet.

However, some improvements are still going ahead and the number of stations offering step-free access from the platform to street level will increase to 65 in time for the Olympics and Paralympics in 2012.

So Mr Baker, as you can see, public transport is certainly improving but I still think we have a long way to go until my journey to and across London could be done as easily as yours.

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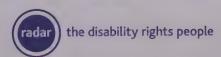
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## **Sportnow** By Paul Carter



He's without a doubt the closest thing that British Paralympic sport has to a superstar, albeit a reluctant one. Because, as **Paul Carter** reports, for wheelchair athlete David Weir, who now has an MBE to add to his glittering collection of medals, he will always be "just one of the boys"

hen he crossed the finish line of the 2011 London Marathon in first place, he officially cemented his position as the most successful male wheelchair marathon athlete of all time.

It was the fifth time the 31-year-old from Wallington, London had claimed the title, something which Weir describes as an "amazing feeling". It was a victory made all the more sweet following the cruel twist of fate in the 2010 marathon, in which Weir suffered heartbreak when getting a double puncture after gaining a commanding lead with just a short distance left to go.

This year however, things went Weir's way. He went into the final straight wheel to wheel with hero, rival and friend, 53-year-old veteran Heinz Frei of Switzerland. However, the

trademark sprint finish once again came to the fore, and with just 300m left to go, Weir powered home for win number five.

So how did he feel this time around?

"I felt good all week and my preparations were perfect," he says.

"Heinz stayed with me but I knew he'd make a surge at the end but thankfully I had enough. I've got a new chair and that has made a massive difference." That new chair has certainly provided him with a new lease of life. Costing over £4,000, the new state-of-the-art racing machine is described by Weir as being "like a Formula 1 car."

For someone who has suffered terrible luck in recent years ahead of major competitions and championships, Weir now finally seems to have put problems with injuries and illness behind him, and is hitting devastating form.

With the only exception of a second place finish in the heats for the 500m at the recent World Championships in January, Weir has won every single race on the track and the road in which he has competed since January.

So, as one of the more senior members of the GB Paralympic squad going into 2012, has his appetite for competition diminished at all since those inauspicious early days?

"I have a tattoo on my chest that's a Japanese symbol meaning 'to win', which pretty much sums me up as an athlete," he says.

Along with the win in the London Marathon, Weir has been gathering medals at a rate of knots in recent months. He claimed victory over the 26-mile distance in New York back in November, before going on to decimate the competition at the IPC World Athletics Championships in Christchurch, New Zealand in January.

Weir took gold in the 800m, 1500m, and 5000m, and was favourite to also take the title in the

marathon, but was among a host of athletes who withdrew over safety fears after organisers failed to ensure that the roads would be closed to traffic during the race.

As someone who has already won top honours at Paralympic Games - he claimed 800m and 1500m gold in Beijing in 2008, and silver and bronze in Athens four years earlier, what lies ahead for the man who will carry the flag for GB in 2012?

"I'll definitely do the marathon in 2012 because my training is specifically geared towards that," he savs.

"I think about it all the time. London is always at the back of my mind. To win the marathon down The Mall would be the pinnacle of my career. What better way to bow out?

"Hopefully I'll stay fit and give it a go. To win gold in London would be a real dream come true."

One thing is for sure, it would be a brave, and perhaps foolish person who'd bet against him doing so.



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# entertainmentnow



sn when you're winning It's a hip-hop combination like no other: signed rap from Marko Vuoriheimo, over low heavy beats and coupled with English lyrics. But it's all aimed at bringing deaf and hearing audiences together,

as the man also known as Signmark tells

**Lucy Howard** 

ou should come and see my concert, and only then decide what's impossible."

Musician Marko Vuoriheimo, whose professional name is Signmark, is just getting into his stride.

Signmark is deaf, and many people assume that deafness and music don't mix. Signmark challenges that assumption.

Signmark is a Finnish rapper who has signed an international record deal, and he's being promoted by Joe Collins. Joe is also deaf and formed JC Promotion to provide accessible music events for deaf and hearing audiences.

Joe's first event is Signmark's UK debut performance this summer.

Signmark's hip-hop style is marked by a clean bassline and strong beats. The low frequencies play a crucial function. The strong vibrations help him feel the music and adapt to the rhythm as he signs his lyrics.

"Hip-hop culture has

always combined visual art and music, blending in social critique. This fits in with our philosophy," says Signmark.

"Music is more than what you can hear! Signmark is something you should see, feel and experience."

Fellow hip-hop artist Brandon Bauer provides the voice for the hearing audiences, and supports all Signmark's albums, videos and performances.

Signmark's unusual blend of music, spoken English and sign language started when he began translating Christmas carols into sign language so his whole family, including his hearing grandparents and deaf parents, could sing together.

"There are still a lot of people who need to come together in the way my family did," he says.

From giving a voice to his own silent community, Signmark has grown to inspire his audiences to "step up together and take responsibility for being the voice of change in society".

Signmark has proved that anything's possible by being an international record label.

"It was a huge turning point," he says. "It was like a validation for me, and maybe even for other people, to show them that the best revenge, the best way to shut up the nonbelievers, back-stabbers and bullies, is to succeed.

"So many thought that I can't. I couldn't and I shouldn't, because I'm deaf,



I hope I can show and inspire others to follow, not in my footsteps, but to follow their own dreams. **Even the craziest** dreams can come true

important thing to him.

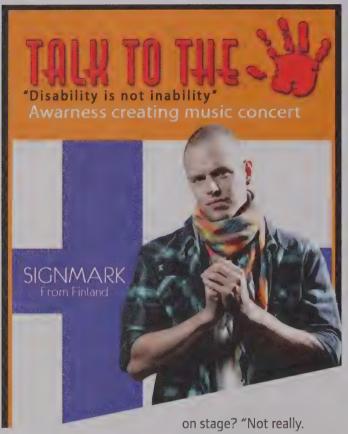
"We have experimented with 'Silent Shout' events, where we learn about differences. Some hearing people feel ashamed to come to the concerts as they don't know how to behave, and some deaf people feel that music isn't for them.

"So we tried to find a way of bringing people together, under the same umbrella, despite the differences in our starting points, with accessible events where everyone could join in. We're happy to find that people feel a sense of community.

"I believe in working collaboratively, trying, learning and sharing, not analysing and talking. My music comes from a need to express myself – and of course a part of my life is also the obstacles I face.

"Is it politics? I don't know... I just love music and I hope my music finds the people who love it too."

With attitude-changing performances around the world, Signmark has a busy



agenda, but he finds time away from music for running, ice hockey, floorball (indoor hockey) and fishing.

When performing, does he have any rituals to help him prepare before going

www.hmvforum.com.

Brandon is always looking for his phone. I just try to get my body awake and warm, as my performing is so much about the rhythm of movement."

The Warner deal was obviously a pivotal career moment, but have there

- ·Signmark will be performing at the HMV Forum in Kentish Town, London, on 4 June, supported by street dance group Flava. Tickets £20. Tel: 0844 847 2405.
- · For more information on Signmark and his music, including performance dates, albums and merchandise, www.signmark.biz.
- To find out more about JC Promotion, including links to Facebook and Twitter, see www.jcpromotion.co.uk.

been any other highs or lows so far?

"A high point was when I got to hold my first album. It had just come hot off the press. I've also had some low points, when I feel things are not moving in the direction I want. I get frustrated easily."

On his future goals, Signmark is passionate. "I want to continue to find new and concrete and innovative ways to make human rights a reality.

"We hope to cooperate with other industries with the power of delivering a message with feeling, like movies, artists, TV and so on. We believe in positive diversity.

"We are travelling and performing across the globe, and we would like to incorporate an awarenessraising message and depth to our events. We think our audiences are ready for it."

That includes audiences in the UK. Both Signmark and promoter Joe Collins are excited about their UK collaboration and about providing an accessible event for Signmark's existing UK followers, as well as potential new ones.

"Signmark is an inspirational performer and an amazing role model for deaf people," says Joe. "I feel that his message is so strong and important to the community here.

"If you had come up to me 20 years ago and said that in 2011 I would be organising a music event for Deaf people, I would have said there was no way that would happen. But it has. Events like this will help to smash down any negative barriers that still exist."

JC Promotions is filling what Joe always saw as a big gap. He has even been asked to do weddings.

"Weddings are not my strength, but maybe in the future - never say 'never'! Keep an eye on us!"

Signmark adds, "I hope I can show and inspire others to follow, not in my footsteps, but to follow their own dreams. Even the craziest dreams can come true."

Signmark has had many dreams come true already, but his future ambitions are limitless.

"I hope to collaborate with more artists. My dream is to open for a famous band. Someone who shares my message. I would love to perform with Bono or Stevie Wonder."

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## webwatch

# Linking to a brighter future



Do you want to change the world or just have a burning passion that you want to share with whoever will listen? E-campaigner Martyn Sibley says there are now tools at your fingertips that really could enable you to leave your mark on the world

ust look at Obama. Thirteen million supporters on his email list, three million online donors, three million Facebook friends, a peak of 8.5m monthly website hits, 800,000 blogs, 35,000 volunteer groups mobilised to run 200,000 offline events and 70,000 fundraising hubs raising \$30 million. No wonder he made President!

But Obama's strategy is transferable to any cause or campaign. For example, a recent issue for disabled people was the potential of Attendance Allowance and Disability Living Allowance to be swallowed up by the new social care reforms. An online epetition collected 23,710 names opposing this. It provoked a Government response stating these benefits would be protected. As importantly, it put social care and disability at the forefront of any further Government policy decisions.

Doing this is simple. You



have to tell your story, build your community and make your call to action.

Start with a compelling

story. I wanted to talk about disability in an inspirational and progressive way. So I started my blog martynsibley.com and began writing about my views. You can also use Facebook, tumblr or myspace as a platform to explain your views and motives. Not only do I write but I show my interesting photos on flickr and upload short video blogs from vimeo (just google these

sites to find them). Then I embed them on my main site. This way my story is more interesting and unique. I also use Twitter and Facebook to update people on real time events allowing supporters to feel a part of what I am campaigning for.

But telling the story is only the beginning. For a while I was adding content but with nobody listening to me. Start by googling disability blogs

and discussion forums. Listen to what others are saying and who seems to have an influence. Then start to participate and air your own views. Use Twitter to follow people with similar views and start twoway conversations. I have met three people through Twitter who I am working on projects with. In time people will engage with you as long as you inspire them in some way. You cannot do it alone and should aim to learn from others as you go.

Then comes the "call to action". For Obama it was asking people to door knock, phone people, give money etc. For the disability e-petition it was as simple as getting people to sign their name to a purpose. The call to action can be small or big.

Just get online, inspire and change something for the better.

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## worklife

## Snoring brings dream of success

New entrepreneur Phillipa James tells us it was all about keeping it in the family when she found an anti-snoring product which gave other people a good night's sleep and her the opportunity of starting her own business



reathing Relief is an anti-snoring dilator I've been developing a market for. It's a product my father invented because he couldn't find anything that gave him any relief from snoring.

My father was a product designer. Experience had taught him that snoring can have quite an impact if, for instance, you're not able to sleep in the same rooom as

your partner. After he'd designed it, I took up the idea, packaged it and brought it to market.

We started out selling it to independents - health food shops, practitioners and so on.

Clinical trials have been done on it with people who have problems snoring and they've had great results.

I was very into having a product that was British and

that didn't use up too many resources. Then I decided I didn't want to go with a big retailer. We found we had the same mission and values as Waitrose, so that seemed like a good place to go.

I've got eight years' experience working in the marketing sector, mostly in the technology industry, but I've also worked in the medical and educational sectors a little bit. I'm a

chartered marketer as well.

I've always wanted to run my own business: it's been my dream. I've had a lot of obstacles and challenges, but I think I was very lucky with what I fell into.

I've met a whole lot of networking groups, with mixed results. Lots of people will say they're going to do things and take you places, but it never happens.

One of the hardest things for me is producing press releases because my biggest area of difficulty is writing. I know what I want to say, but I can't necessarily format it right and get it in the right order.

Business plans were also an absolute nightmare. For a whole year I was planning things and trying to get them onto a spreadsheet. In the end I decided to do it all in Powerpoint, which everyone's completely accepted.

For the future I'd like to create this British brand and export it. But any product we do has to help people. I just couldn't market a product I didn't believe in.

- · Phillipa James was talking to Ian Macrae.
- · · More information about Phillipa and the Breathing Relief anti-snoring device at breathingrelief.com



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**RENAULT KANGOO** EXPRESSION, Sept 2005 (55 reg) 1.6 16v, automatic, pas, air con, alloy wheels, e/windows, c/locking, CD/Radio, 1 owner, 17,500 miles, FSH (Renault main dealer) MOT Sept 2011, VGC. Gowrings conversion, 4 point wheelchair securing system, adjustable diagonal & lap seat belt, lightweight ramp, electric winch, seats 5 including wheelchair, front passenger swivel seat + original seat + 2 rear seats. Genuine reason for sale, £6,000 ovno. Tel: 01420 23557 (Surrey/Hants) or email: p.etherton275@btinternet.com

#### **VOLKSWAGEN CADDY LIFE**

1.9, diesel, auto, registered Dec 07 (57 plate), air con, central locking, e/windows, CD player, silver. With Lewis Reed Conversion incl lowered floor

with lightweight fold-out ramp and inertia belts for wheelchair stability. Carries a maximum of 6 including wheelchair. Only one owner from new, 4,200 miles, fsh, in immaculate condition inside and out, £17,250 ono. Tel: 020 8866 9504 (Harrow) or mobile: 07885 291015, email: tonyharvie@hotmail.com

**VEXEL QUOVIS 1.2**, white, auto, only 1,000 miles, built 2007, imported from Spain in 2008. MOT is due in November 2011. Drive from wheelchair vehicle, push button for wheelchair rear access via ramp to front driving position. Fsh. Top speed 50 mph. In excellent condition and only one registered owner. £3,200. Tel: 07903 882299 (Teddington, SW London) or email: andrewdownie51@hotmail.com

#### **CITROEN DISPATCH 1.9,**

diesel, reg Jan 2005. Fully lowered floor space for large wheelchair. Gowrings conversion. Colour: metallic gun metal grey. Seats 7 incl wheelchair. MOT till Dec 2011. 38k miles, 1 owner from new. £6,950 ono. Tel: 0141 889 3374 (Glasgow) or email: theejaquar@hotmail.com

#### **RENAULT KANGOO**

**AUTHENTIQUE** 1.2, air con, pas, ABS, blue, only 11k miles, registered 1994 (04 plate). Constables Wheelchair Conversion incl lightweight manual ramp at rear with necessary wheelchair fixings and belt for stability. Seat behind front passenger, carries a maximum of 4 including wheelchair. 2 owners from new, fsh, MOT expires late Oct, in immaculate condition, £4,950. Tel: 02380 292020 (New Forest) or email: Richywillis1@aol.com

Cont'd pg 64

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christine.cooke@ntlworld.com

#### **BALDER FINESSE ELECTRIC**

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IBIS XC POWERDRIVE, max user weight 25 stone, total weight 6.3 stone, length 40.9" and width 24.6". Perfect seating posture and comfort are crucial for the more independent individual, at home or in hospital. For this reason, the Ibis XC push wheelchair incorporates the individually adjustable Sedeo seating system. A person's seating posture can easily be changed with ease to operate 30 degree 'tilt-in-space' adjustment, providing comfort while helping to prevent pressure problems. Maximum comfort, excellent driving, Power Support attendant controlled. In excellent condition, cost £4,000, still under warranty until October 2011. Accept £3,500 ono. Buyer collects. Tel: 01733 567587 (Cambs) or email: gerardandjannet@ btinternet.com

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#### WARNING

We have been warned about a scam involving people from overseas who say they want to buy a product and who offer to pay using cheques, Western Union money transfers and certified cheques. Although no Disability Now readers to our knowledge have been hit by this, please be particularly wary of accepting cheques from overseas. For more information, visit the Metropolitan Police website.

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#### DN DEADLINE

July 2011 published 30 June. Classified deadlines: Booking: 6 June. Copy: 8 June.

## backlash



# Airport insecurity

Even when going on holiday, **Paul Carter** finds himself being treated just that little bit differently

've just been on holiday! It happens rarely so deserves an exclamation mark. Though the experience wasn't helped by the particular airline I travelled with. I won't name them, but let's just say I've had more entertaining times at funerals than the combined three-and-a-half hours I spent stuffed inside their soul-destroying miserycraft. Speaking of funerals, the cabin crew looked like they were currently attending one such was the joyless nature of their demeanour, and the fact that any simple request was greeted with a look like you'd just asked them if they could possibly help apply your haemorrhoid cream.

Having said all that, what really got me thinking was what happened before even getting on the plane.

I have absolutely no idea what it is about me, but every single time without fail, I get pulled over for just that little bit more attention by the security people than anyone else.

Now, I'm not one for social profiling, and in these



days I have to go somewhere where you need to go through one of those giant metal detector thingys, I get pulled aside as if I'm some imminent threat to national security

days of campaigning for equality, it's a given that disabled people can be criminals and ne'er-do-wells just as much as the next man. Or woman even. However, you'd have to say

that on a sliding scale of people who look most likely to have evil intent, a man with no arms and legs would probably feature somewhere between small children and people who've just smoked a spectacular amount of cannabis.

And yet, every time these days I have to go somewhere where you need to go through one of those giant metal detector thingys, I get pulled aside as if I'm some imminent threat to national security. Even when I warn them beforehand. "My legs will set it off," I say. And it does. Then they bring out the

handheld metal detectors – you know the ones, they look like some sort of Martian death ray. Then they wave it around my legs, making weird noises and playing me like a Theremin.

On my way through Stansted security I got frisked so vigorously I felt like I should have bought the man a drink afterwards.

The strangest one ever though was on my last trip to Europe a couple of years ago, when I was returning home from Amsterdam (I know, I know.)

Without a frighteningly vaque "one moment sir", one of the security staff took my chair and wheeled me aside. Now, let me tell you, there's no moment more terrifying than when a Dutchman wearing surgical gloves wheels you away towards a curtained cubicle. He then proceeded to give a fingertip search around the top of my prosthetic leq. It remains to this day one of the strangest 20 seconds of my life, and even more worryingly, not that unpleasant.

# Wheelchair Drivers

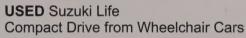
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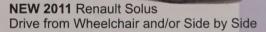
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2008/9

2007/9

2007/9

2002/8

2006

2009

2001

2002/6

Volkswagen Caravelle, drive from wheelchair or transfer Volkswagen T5 Shuttle, drive from wheelchair or transfer Renault Solus, drive from wheelchair or side by side swap Sirus Fiat Qubo, drive from and/or up-front passenger swap

Renault Solus, drive from wheelchair

Sirus Volkswagen Caddy, drive from wheelchair

Sirus Renault Kangoo, drive from, choice of 5

Kia Sedona Pilot, drive from/side by side, choice of 3

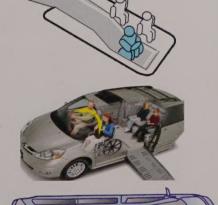
Chrysler Entervan, drive from or up front, choice of 3

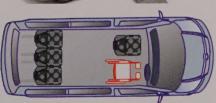
VW Transporter High Roof, fully automated + transfer seat

Mercedes Sprinter, fully automated drive from wheelchair

Suzuki Life, drive from wheelchair, choice of 5

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